

# Patient Perspectives brought to the Fore for Diabetes Care: Descriptions as well as Development and Testing of the Diabetes Questionnaire

Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligen försvaras i Jubileumsaulan, Sahlgrenska universitetssjukhuset, Göteborg, den 29 november, klockan 13:00

av Maria Svedbo Engström

Fakultetsopponent:

Professor Margareta Kristensson, Linköpings universitet, Linköping, Sverige

## Avhandlingen baseras på följande delarbeten

- I. Svedbo Engström, M, Leksell, J, Johansson, U-B, Gudbjörnsdottir, S. What is important for you? A qualitative interview study of living with diabetes and experiences of diabetes care to establish a basis for a tailored Patient-Reported Outcome Measure for the Swedish National Diabetes Register. *BMJ Open* 2016;6:e010249. doi: 10.1136/bmjopen-2015-010249
- II. Svedbo Engström, M, Leksell, J, Johansson, U-B, Eeg-Olofsson, K, Borg, S, Palaszewski, B, Gudbjörnsdottir, S. A disease-specific questionnaire for measuring patient-reported outcomes and experiences in the Swedish National Diabetes Register: Development and evaluation of content validity, face validity, and test-retest reliability. *Patient Education and Counseling* 2018;101(1):139-146. doi: 10.1016/j.pec.2017.07.016
- III. Svedbo Engström, M, Leksell, J, Johansson, U-B, Borg, S, Palaszewski, B, Franzén, S, Gudbjörnsdottir, S, Eeg-Olofsson, K. Health-related quality of life and glycaemic control among adults with type 1 and type 2 Diabetes – a nationwide cross-sectional study. *Health and Quality of Life Outcomes* 2019;17(141):1-11. doi: 10.1186/s12955-019-1212-z
- IV. Svedbo Engström, M, Leksell, J, Johansson, U-B, Borg, S, Palaszewski, B, Franzén, S, Gudbjörnsdottir, S, Eeg-Olofsson, K. New diabetes questionnaire to add patients' perspectives to diabetes care for adults with type 1 and type 2 diabetes – Nationwide cross-sectional study of construct validity assessing associations with generic health-related quality of life and clinical variables.

*Manuscript.*

**SAHLGRENSKA AKADEMIN  
INSTITUTIONEN FÖR MEDICIN**



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## Abstract

**Aim:** The overall aims were to describe perspectives of living with diabetes, to develop a patient-reported outcome and experience measure for the Swedish National Diabetes Register, and to initiate the evaluation of evidence of measurement quality for that measure. A further aim was to describe health-related quality of life and to assess its associations with glycaemic control.

**Methods and results:** In **study I**, aspects important to adults with diabetes embracing experiences of daily life and support from diabetes care were identified through 29 semi-structured qualitative interviews. In **study II**, those aspects were used to develop the Diabetes Questionnaire. Expert reviews, six cognitive interviews, and a regional survey of 1,599 adults with diabetes yielded supporting evidence for content and face validity, test-retest reliability, and answerability. For **studies III-IV**, the Diabetes Questionnaire and the SF-36v2 were presented to 4,976 adults with diabetes in a nationwide cross-sectional survey. In **study III**, adjusted regression analyses showed that adults with high-risk glycaemic control have lower health-related quality of life than those with well-controlled glycaemic control. In **study IV**, correlation, machine learning and adjusted regression analyses demonstrated support for construct validity. The Diabetes Questionnaire captures some SF-36v2 dimensions while adding information not targeted by clinical variables or the SF-36v2 and it is sensitive to differences between groups of glycaemic control.

**Conclusion:** The Diabetes Questionnaire has the potential to support clinical meetings and assessments and hence help to bring patients' perspectives to the fore for diabetes care.

**Keywords:** Diabetes Mellitus; Patient-Reported Outcome Measures; Qualitative Research; Surveys and Questionnaires; Cross-Sectional Studies